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AUTHOR Pierson, Margaret Hauser
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ABSTRACT

Designed to provide parents with basic information about the physical and emotional aspects of amputation, the booklet gives information about the grief response, body image, phantom limb sensation, stump care, and the prosthesis. The section on the grief process describes normal reactions to loss: denial, anger, bargaining, depression, and acceptance. The second section gives five suggestions for helping a child rebuild his body image. Section 3 focuses on helping children accept phantom limb sensations. The section on stump care includes reference to exercise, skin care, and wrapping. Following the section dealing with care of an artificial limb (prosthesis), the booklet presents potential sources of information and of assistance with the expense of medical care for the amputee. (LH)

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Notes to Parents — When Your Child Has Undergone Amputation

by
Margaret Hauser Pierson, R.N., M.S.N.

Meyer Children's Rehabilition Institute
University of Nebraska Medical Center

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Notes to Parents — When Your Child Has Undergone Amputation

by
Margaret Hauser Pierson, R.N., M.S.N.

Additional Artwork by LaVonne Latham
Illustrations by Sharon Swift Rife, R.N., M.S.N.

Edited by Mary Margaret Simpson
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ACKNOWLEDGEMENTS

I met Paula and her family when I was a graduate nursing student. Paula, then nine-years-old, was hospitalized for a serious injury to her arm. The arm was amputated following an unsuccessful attempt to restore its damaged blood supply.

In an effort to help Paula and her parents, numerous local agencies were contacted in search of written material which would explain some of the physical and emotional aspects of amputation. Some of the agencies contacted were: Services for Crippled Children, Easter Seal Society, Hotline for the Handicapped, March of Dimes, Community Health Nurses, Education Division of the State Health Department, Meyer Children's Rehabilitation Institute, a local prosthetist, the physician's office, and several local hospitals. The agencies were most willing to assist but unable to locate patient educational materials for this situation. Yet, the majority of the agency contact persons recognized and verbalized a need for some sort of informational booklet.

In response to the identified need, this booklet for parents was developed. I would like to thank Jeannene Boosinger, R.N., Ph.D., Associate Professor, University of Nebraska Medical Center College of Nursing Graduate Program, for her encouragement and guidance in this endeavor, and Cordelia Robinson, R.N., Ph.D., Clinical Psychologist, Meyer Children's Rehabilitation Institute, and Jan Lucas, R.N., M.N., Assistant Professor, University of Nebraska Medical Center College of Nursing Graduate Program, for their review and critique of the manuscript. I would also like to acknowledge the assistance of the pediatric nurses at Lincoln General Hospital (Lincoln, Nebraska) and the parents who participated in a field test of the booklet to determine its effectiveness as a teaching tool.

— Margaret Hauser Pierson

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INTRODUCTION

Your child's amputation is an overwhelming experience for you and your child. This booklet is not intended to answer all of your questions. Rather, it is designed to provide you with basic information about the physical and emotional aspects of amputation. It will give you information about what is happening now and give you some ideas about what the future holds. Keep this booklet — you may wish to refer to it later.

Potential sources of information and assistance with the expense of medical care for the amputee appear at the end of this booklet. A brief list of other pamphlets that might interest you is also included.

THE GRIEF RESPONSE

The pain and sorrow that you and your child feel are much the same as that experienced following the death of a loved one. Amputation represents a loss — the loss of a body part. The body part (be it a hand, an arm, a foot, or a leg) was a useful tool in your child's day-to-day activities. You, as a parent, feel pain and sorrow for the injury your child has endured and for his or her loss.

Dr. Elisabeth Kubler-Ross is a name with which you may be familiar. She studied the grief process and described normal reactions to loss. Dr. Ross identified five stages of grief: denial, anger, bargaining, depression, and acceptance. Not everyone goes through every stage, in the same order, or at the same rate. You, your spouse, and your child may not progress through these stages at the same rate or in the same sequence.

So that you might understand some of the feelings you have and learn that those feelings are not abnormal, here is a brief description of those five stages.

Denial. "No, it can't be!" This is a typical reaction when one learns of a tragedy or of a loss. You may have just learned that your child has cancer and must have a leg removed or that your child was in an accident and a damaged arm cannot be saved. Dr. Ross says that this "numbness" helps to cushion the impact of the news.

Anger. "Why me?" What has happened does not seem fair. Often God is the target for this anger. Dr. Ross suggests that anger is not only permissible but inevitable and that "God can take it." Anger often alternates with guilt. You may feel guilty for being angry or blame yourself for what has happened to your child. However, you cannot assume responsibility for things that are not under your control.

Bargaining. "Yes, it's true, but . . ." In this stage, we bargain with God. We promise to do something in exchange for the news that the arm can be saved or the leg won't need to be removed.

Depression. "Yes, it's true." You are mourning the child's loss of an extremity, of some functional ability, and maybe even your shattered dreams for the child's future. You may be unable to eat, to sleep, to concentrate, and may even feel physically ill.

Acceptance. "It is true and we must go on." The numbness and the depression are beginning to fade and your energy can be channeled into adjusting to the change in your life and your child's life.

These feelings are normal stages in response to loss. Remember that you, your spouse, and your child may progress through these stages at a different rate or in a different order.

Sharing your feelings and the passage of time enable you to move through the stages to acceptance. You may need someone to talk to about your feelings — possibly your minister, the hospital chaplain, or a nurse.

One father said he thought his daughter was doing better following the amputation than he was. It seems that is often the case. Yet, your child has suffered a loss and is going through the same stages you are. Your child needs your love, acceptance, and honesty to move through the grief process. Your child also needs to be able to express his or her feelings. If you and your child are able to share feelings you should do so. Still, it may be too painful at first to hear your child express the same feelings you have. Your child should be allowed and encouraged to talk with someone close. That person may be a minister, a nurse, or in some cases, a teacher.

Your progress through grief is a family process and you will need to help each other. Whether as a family or individually, you will probably find it helpful to establish some outside support to help you through these early stages.

BODY IMAGE

The term "body image" refers to the way that we feel about ourselves and how we imagine we look. The way that we feel about ourselves affects our attitude towards life and the way that we interact with other people. On days when you feel good about yourself and you look nice, you probably feel happier and are more interested in the people around you.

When someone's appearance changes — after a weight gain or hair loss, for example — that person may not feel as good about himself. An individual may feel self-conscious, unattractive, and prefer to be alone.

Your child may respond to amputation in a similar manner. A child's body image and attention to his or her appearance changes as the child grows older. The younger child pays much less attention to appearance than does the adolescent. The adolescent is especially conscious of changes as the body matures from that of a child to that of an adult.

The child's body image is influenced by the attitude of others, the child's age, and the degree of change in body appearance. The quality of the child's relationships with people is very important in rebuilding body image after amputation.

The following are suggestions you might be able to use to help rebuild your child's body image:

1. Continue to demonstrate love for your child. This will provide reassurance that the amputation does not change your feelings.

2. Encourage independence in self-care (such as teeth brushing and hair combing) because it will help build the child's physical strength and self-confidence.

3. Attend to your child's physical appearance. While in the hospital, children will probably be more comfortable in their own pajamas. In addition, their hair should be combed and their teeth brushed.

4. The doctors, nurses, and physical therapists will call the remaining part of the extremity the "stump." You will need to become familiar with that term and the appearance of the stump. This will help your child realize that the stump is an acceptable part of the body.

5. Before a child leaves the hospital the staff will attempt to explore the child's concerns about returning home and to school. Answers are selected for questions the child might be asked. (For example: How did that happen? How does it feel? How do you eat with one hand? How does the artificial leg stay on?) This technique is intended to increase the child's comfort upon returning to school. He or she should know it's okay to say, "I don't care to talk about it now." The teacher may be enlisted to explain to other students how the child will look and that the child wishes to be treated the same as before the amputation. Rebuilding your child's body image takes time. These measures may be used to support the child during the adaptive process.

Most amputees are able to resume the majority of their pre-amputation activities. But, the amputee may need to learn a few all over again. For instance, one nine-year-old amputee learned to ride her bicycle and play pool again within three weeks of an accident that resulted in the loss of an arm. To some extent the amputee may only be as handicapped as she allows herself to become.

PHANTOM LIMB SENSATION

Most persons experience the sensation that an amputated body part is still present after amputation. It is helpful if the child knows this before surgery. If not explained prior to surgery, the child should be told afterwards.

Former patients explain that phantom limb sensations include itching, burning, cramping, or just feeling like the missing part is still there, perhaps in a certain position. All these are normal sensations, although experts have not agreed on the cause. A few amputees actually experience pain where the body part was. The best thing to do if that happens is to keep busy and try to think of other things. In most instances it is temporary.

When children do not expect but then experience a phantom limb sensation it seems to interfere with their acceptance of the amputation. The information given here will prevent you from being concerned by your child's report of a phantom sensation and enable you to explain that it is normal.

STUMP CARE

Proper care of the stump is necessary to ensure useful function of the remaining joints of the amputated limb. Such care will also increase the likelihood that an artificial limb will be comfortably and efficiently used.

Exercise. It is important that the remaining joints of the amputated limb do not become stiff. Exercise will also keep the muscles of the extremity strong. Good joint and muscle function improve the usefulness of that extremity when an artificial limb is obtained.

All remaining joints should be maintained in full range of motion, that is, be able to move in those directions they moved prior to the amputation. A nurse or physical therapist can demonstrate and assist with these exercises during the early days after surgery.

The amputee should also lie on his stomach for at least one hour four times a day to ensure that the joints do not lose the ability to straighten out completely. This is especially important for lower extremity (leg) amputees, but can be useful for upper extremity (arm) amputees when the elbow remains. The elbow should be straightened and may rest upon a pillow for support. A nurse or physical therapist can also demonstrate these positions for you.

Skin Care. After the incision on the stump is well healed, the doctor will instruct the amputee to wash the stump daily. The stump should be washed gently with warm water and a mild soap. Some experts suggest *Dial* or *Ivory*, although you should ask for your physician's preference. You must be sure that all of the soap is rinsed from the stump because remaining soap could irritate the skin. The stump should not be soaked for long periods since that may soften skin and cause swelling. Gently pat the stump dry — rubbing may irritate the skin. Experts recommend washing the stump at night to allow thorough air drying before applying the artificial limb.

Never use lotion or alcohol on the stump. Lotion may soften the incision and alcohol is a drying agent. If blisters or abrasions (irritations) develop, the prosthesis should not be worn and it may be necessary to consult the prosthetist (maker of artificial limbs) or physician.

Wrapping. Elastic bandages are used to prepare the stump for fitting with an artificial limb by shaping and shrinking it. Your doctor, a nurse, or physical therapist can demonstrate the proper method of wrapping the stump. The method is slightly different according to the extremity involved and the level of amputation.

Elastic bandages should be changed and laundered daily. They should be hand washed in mild soap and warm (not hot) water and rinsed thoroughly. Squeeze the water out (wringing can ruin the elastic) and lay the bandages on a flat surface to dry. Hanging to dry or placing in a dryer can also ruin the elastic.

The physician and prosthetist will decide how long the stump will need to be wrapped. Some amputees do not need to wrap the stump once they have a well-fitted prosthesis. The elastic bandages are also helpful for treating temporary swelling of the stump.

THE PROSTHESIS (ARTIFICIAL LIMB)

The doctor will determine when the amputee is ready to be fitted for a prosthesis and what type of prosthesis to use. A doctor, nurse, or physical therapist may be able to show you pictures of what a prosthesis will look like. Physical therapy and practice will be required to help the amputee learn to use the prosthesis efficiently.

Care of the prosthesis. The prosthesis will require some care, too. The "socket," or the place where the stump fits into the prosthesis, should be washed out with warm water and mild soap. Use a cloth dampened with soapy water to wipe out the socket. This should be done daily during the summer and every two to three days during the remainder of the year. Dry the socket thoroughly. It is best to do this at night so that the socket will air dry before it is reapplied. Moisture in the socket could be irritating to the stump.

A stump sock is placed on the stump before applying the prosthesis. It should be changed daily and washed before the perspiration in it dries. Wash it in warm water and mild soap, rinsing thoroughly. It is best to allow the sock to air dry since it may shrink if placed in a dryer.

Remember that attention to stump care and care of the prosthesis increases the likelihood that an artificial limb will remain comfortable and useful. A child who is old enough can gradually begin to assume responsibility for stump care.

ADDITIONAL INFORMATION

Two national offices are potential sources of information and assistance on medical care for the amputee:

National Amputee Foundation
12-45 150th Street
Whitestone, New York 11357

The Easter Seal Society for
Crippled Children and Adults
2023 West Ogden Avenue
Chicago, Illinois 60612

Specific publications which you might request from these two offices are listed in this booklet under "Suggested Reading."

Most states and cities have local or regional offices of these two organizations. In addition, local chapters of the Visiting Nurses Association and community health departments have information. Other sources might include the hospital which performed the surgery, the physician's office, or the prosthetist.

A few local agencies in your area may be able to assume the cost of medical care for amputees who qualify for their services. Contact your local Health Department for information and referral.

SUGGESTED READING

Pamphlets

National Amputation Foundation —
- Consumer Survival Kit
- Handbook for Lower Extremity Amputees
- Single Handed for Arm Amputees
- Things to Know About Amputation and Artificial Limbs
- Tips for Amputees

The Easter Seal Society —
- Self-Help Clothing:
  - For Children Who Are Physically Disabled
- Using Everything You've Got
- View of Life
- Why Did This Happen?

Books

Kubler-Ross, E. *Death: The final stage of growth*. Englewood Cliffs, N.J.: Prentice-Hall, Inc., 1975. (Provides information on stages of grief.)

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Ritchie, J. A. Children's adjustive and affective responses in the process of formulating a body image following amputation. *Maternal-Child Nursing Journal*, 1977, **6**, 25-35.

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A REQUEST

While you were reading this publication did you think of areas you would have liked to have seen explored which were not? As a parent, can you recall challenges which you and your child faced before, during, or after an amputation which were not addressed here? Perhaps as a physician, nurse, or other professional there were certain problems you wish had been discussed.

Write us. We welcome your comments and suggestions for the next edition.

Media Resource Center
Meyer Children's Rehabilitation Institute
University of Nebraska Medical Center
444 South 44th Street
Omaha, Nebraska 68131
(402) 559-7467

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